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HINTS & KINKS

Methods for understanding childhood trauma: modifying the adverse childhood experiences international questionnaire for cultural competency

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Adverse childhood experiences (ACEs) research based in the United States demonstrated that traumatic stress in childhood can cause negative physical and mental health outcomes (Stumbo et al. 2015; Normal et al. 2012; Waldman et al. 2011). Many developing countries lack extensive research on ACEs and comprehensive data on exposure to childhood trauma (Anda 2009). The World Health Organization (WHO) ACE international questionnaire (ACE-IQ) highlights multiple types of abuse, neglect, and violence while broadening the definition of traumatic stress to include more globally relevant concerns (WHO 2017).

The ACE-IQ requires modifications to match the cultural context of the population. This is of high importance due to the need to develop and implement culturally relevant survey mechanisms specific to communities and interventions aligned with community needs. Cultural relevancy is formulated by addressing cultural and contextual differences between the priority population and other populations (Alegria et al. 2004; Kumas-Tan et al. 2007) and is depicted by a specific location, cultural mores, and terminology. The goal of this project was to modify the ACE-IQ for cultural context in a low-resource, underserved community in South Africa (SA). Munsieville, SA is an undeveloped township with reports of local children seeking assistance following acts of violence (Project Hope UK 2017). It is suspected that children living in townships are disproportionately affected by violence and family dysfunction (Ward et al. 2007). These circumstances made Munsieville an ideal community to examine ACE prevalence after modification of the ACE-IQ.

Residents of Munsieville aged 18 and older were eligible to participate in the study and recruited through community leaders. Local facilitators were used to conduct three focus groups and one interview to gain insight into proper modification of the ACE-IQ. Groups included: females 18–29 ($N = 6$); females 30–50 ($N = 5$); males 18–29 ($N = 5$); and a male 30–50-year-old ($N = 1$). Discussion of the overall project and operational definitions of trauma, abuse, neglect, and violence for this setting were completed at the beginning of each session. For each question on the ACE-IQ, participants were asked:

1. Is this question appropriate for your community?
2. Should anything be changed on the question?
3. Can it be understood by community members?
4. Are there any words that need to be changed?
5. Are there any questions that need to be added?

Feedback from participants examined questions for appropriateness, understandability, modifications, and needed additions. Focus groups and interviews were audio recorded and notes were taken. Sessions were transcribed for thematic analysis, following Braun and Clarke's method (Braun and Clarke 2006), allowing researchers to analyze and modify the ACE-IQ to match the priority population (Fereday and Muir-Cochrane 2006). Four trained coders independently analyzed data and identified themes to modify the ACE-IQ. Coders provided themes for each question and determined whether to: (1) include

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question as written, (2) include question with modifications, or (3) delete question. Any questions or responses to be included with modifications were discussed and agreed upon by all coders. Coders reviewed additional questions suggested and determined how questions should be worded for inclusion. Coders modified 23 questions and response options for four questions. New questions were included to elicit more information on demographics, community needs, and behavioral risk factors. Two questions were deleted, as they were determined to be irrelevant to community context. A revised ACE-IQ was then created to serve as a method for measuring traumatic childhood experiences in Munsieville. The lead researcher reviewed the modified questionnaire and sent the modified ACE-IQ to key stakeholders in Munsieville to be shared with focus group participants for final approval. Developing the appropriate and relevant wording led to a restructuring of questions and an increase in the reliability and cultural relevancy of the survey, providing a region-specific ACE-IQ.

The ACE-IQ is a vital resource for measuring childhood exposure to trauma. However, it is necessary to adapt the questionnaire to the community in which it is being administered (WHO 2011). Without adapting the questionnaire to use culturally appropriate questions and terminology, respondents may not provide answers consistent with the questions and questions may not be understood. Questions related to sexual abuse were the most difficult to discuss and word appropriately. Respondents may have found it distressing to reveal these emotional experiences due to feelings of shame, self-blame and fear. In SA, studies indicate that lack of an environment that encourages individuals to come forward when they experience sexual violence is associated with underreporting (Jewkes and Abrahams 2002). The use of well-designed questionnaires with sensitive wording, including triggers to improve recall, has been found to increase rates of disclosure of traumatic experiences (WHO 2001). Additional questions stemming from the focus groups are pertinent and shed light on context-specific ACE issues relevant to this community. Use of local words (e.g., shebeen instead of bar; sjambok instead of stick) will ideally provide more correct and truthful responses.

Our study had several strengths. Through focus groups, we captured opinions from various ages and both sexes. We reached information saturation by the end of the second focus group. Responses were coded by a trained group of independent researchers and the modified survey was reviewed by all. The modified survey was then given back to local stakeholders and reviewed for approval. This pilot study demonstrates that the modified questionnaire provides a comprehensive measure of childhood trauma. Field testing the questionnaire in community to ensure its relevance to ACE issues led to increased community participation during implementation of the modified ACE-IQ survey in early 2017, which was the first step to quantitatively validate the survey.

Findings of this study are limited by the lack of a focus group for males aged 30–50 years due to restrictive work schedules that prevented participation. The qualitative nature of our study implies that it is vulnerable to selection bias, and we may have inadvertently selected participants whose views vary from those of the community. Finally, our study may not include all forms of childhood adversity. It is possible that a specific type of adversity relevant to the community was not listed on the questionnaire or discussed in the focus groups.

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Compliance with ethical standards

Conflict of interest We have no conflicts of interest to disclose.

Ethical approval All authors have read and approved this final version. The project was reviewed and approved by the University IRB and the non-government organization in country partner.

Informed consent Informed consent was completed by all focus group and interview participants.

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